

CHAPTER NO. 965

HOUSE BILL NO. 1326

By Representatives Eckles, Caldwell, Davidson, Hood, Bone, Robinson, Walley, McDonald, Fowlkes, Williams, Head, Kisber, McMillan, Hargrove, Armstrong, Brenda Turner, Curtiss, Rhinehart, Hagood, Harwell, Godsey, Mumpower, White, Fraley, Ridgeway, Maddox, Fitzhugh, Jackson, Tidwell, Lois DeBerry, Bowers, Pruitt, Langster, Cooper, Towns, Hassell, Chumney

Substituted for: Senate Bill No. 1678

By Senators Harper, Herron, Crowe, Williams, Kurita

AN ACT to amend Tennessee Code Annotated, Title 68, Chapter 5, Part 5, relative to a birth defects registry.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Title 68, Chapter 5, Part 5, is amended by adding the following as a new section to be appropriately designated:

Section _____. (a) The General Assembly hereby finds and declares that birth defects represent problems of public health importance about which too little is known; that these conditions impose enormous physical, emotional, social, educational and financial burdens on individuals, families, communities and the State; and that a system to obtain more information about these conditions could result in development of preventive measures to decrease their incidence in the future. Therefore, it is the intent of the General Assembly in enacting this section to accomplish all of the following:

(1) To maintain an ongoing program of birth defects monitoring statewide. "Birth defect" as used in this section means any structural or biochemical abnormality, regardless of cause, diagnosed at any time before or after birth, that requires medical or surgical intervention or that interferes with normal growth or development.

(2) To provide on, at least, an annual basis information on the incidence, prevalence and trends of birth defects.

(3) To provide information to determine whether environmental hazards are associated with birth defects.

(4) To provide information as to other possible causes of birth defects.

(5) To evaluate the current prevention initiatives undertaken by the State, and to give guidance for improvement of these initiatives or for the addition of new prevention strategies.

(6) To provide a case referral element whereby the families of children born with birth defects are provided information on public services available to them and their child.

(b) (1) There is established a birth defects registry in the Department of Health.

(2) The Commissioner of Health shall establish an advisory committee to guide the department in establishing and maintaining the registry. The committee shall include members representing the disciplines of obstetrics and gynecology, pediatrics, genetics, epidemiology, biostatistics, hospital administration, state agency service providers, parents of children with birth defects, members of interested non-profit organizations and members of the general public. The advisory committee shall annually evaluate the adequacy of the registry and report their findings annually to the appropriate standing committees of the General Assembly.

(3) The department shall maintain a system for the collection of information necessary to accomplish the outlined purposes of this section. For purposes related to the registry, the department shall have access to any medical record that pertains to a diagnosed or suspected birth defect, including the records of the mother. Providers acting pursuant to this section shall not be liable for the release of medical records as authorized by this section. The department will develop and disseminate information about the birth defects registry to the participating perinatal centers that will be made available to the family which explains and describes the purpose and process of the registry and how confidentiality will be protected. The Commissioner of Health, with guidance from the advisory committee, shall promulgate by rule a mechanism for the active verification of reports through the use of multiple sources.

(4) The registry shall collect information on birth defects, whether they occur as live births, stillbirths, or fetal deaths.

(5) The registry shall collect information on birth defects diagnosed in children up to the age of five (5) years.

(6) The registry shall be implemented as a pilot project to include reporting by any of the five (5) designated perinatal centers choosing to be included in the pilot project. Perinatal centers participating in the pilot project shall report birth defects registry as required by the Commissioner of Health.

(c) The department, with guidance from the advisory committee, shall establish a program in the registry for referring families of children born with birth defects or the mothers of children lost to birth defects to available appropriate State resources. In order for a family of a child with a birth defect to participate in the referral program established by this subsection the child's parents or legal guardian must contact the department and request to be included in such program.

(d) The staff of the registry shall use the information collected pursuant to this section and information available from other reporting systems and health providers to conduct studies to investigate the causes of birth defects, and to determine and evaluate measures designed to prevent their occurrence. The department's investigation shall not be limited to geographic, temporal, or occupational associations, but may include investigation of past exposures.

(e) (1) All information collected and analyzed pursuant to this section shall be confidential insofar as the identity of the individual patient is concerned and shall be used solely for the purposes provided in this section; provided that the commissioner may provide access to those scientists approved by the advisory committee who are engaged in demographic, epidemiological or other similar studies related to health, and who agree, in writing as nonstate

employees, to be identified and coded while maintaining confidentiality as described herein and to the centers for disease control (CDC) for inclusion in the National Birth Defects Registry.

(2) The department shall maintain an accurate record of all persons who are given access to the information in the registry. The record shall include:

(A) The name of the persons authorizing access;

(B) The name, title, and organizational affiliation of persons given access;

(C) The dates of access;

(D) The specific purpose for which the information is to be used; and

(E) The results of the independent research.

(3) Nothing in this section shall prohibit the publishing of statistical compilations relating to birth defects or poor reproductive outcomes that do not in any way identify individual sources of information.

(4) (A) Any individual who willfully discloses information made confidential by this section, unless permitted to do so by subdivisions (1) and (3), has committed a Class A misdemeanor.

(B) Any individual who negligently discloses information made confidential by this section, unless permitted to do so by subdivisions (1) and (3), has committed a Class B misdemeanor.

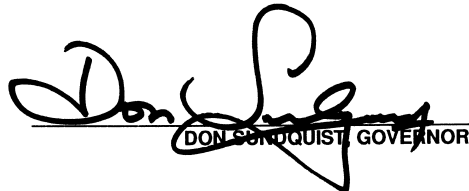
SECTION 2. This act shall take effect July 1, 2000, the public welfare requiring it.

PASSED: June 9, 2000


JIMMY RAIFEH, SPEAKER
HOUSE OF REPRESENTATIVES


JOHN S. WILDER
SPEAKER OF THE SENATE

APPROVED this 21st day of June 2000


DON SUNDQUIST, GOVERNOR